











Partnership for Hope

Expanding and Continuing to Change Lives

NOVEMBER 2013







Missouri Association of Counties for Developmental Disabilities Services



November 1, 2013

Nearly three years ago, we launched the Partnership for Hope program to provide earlier access to services for Missouri individuals with developmental disabilities, and their families. The idea behind the Partnership is simple: end the wait for services; avoid or delay the need for institutional placement; and keep families together.

We knew the demand was there and the response has been overwhelming. Already, the partnership has helped thousands of people with developmental disabilities work toward reaching their full potential.

As we continue to move forward, we will expand this vital program to more Missourians. This unique and innovative partnership between local, state and federal

resources provides the opportunity that many persons with developmental disabilities need to become full participants in their communities.

I am proud to say today the Partnership for Hope serves more than 2,600 Missourians from 99 counties and the city of St. Louis. This program has had a profound impact on the lives of individuals and families in Missouri. Together we can continue to help the many individuals and families faced with challenges by providing the right interventions at the right time.

Sincerely,

Governor Jay Nixon





"This unique and innovative partnership between local, state and federal resources moves our system of supports and services away from a crisis-driven response to a preventive and enabling system of care."

- Governor Jay Nixon

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"This program exemplifies the best of federal, state and local government working together to improve the lives of Missourians with disabilities."

- Governor Jay Nixon

The Partnership Continues to Bring Hope for the Future



A creative program that more broadly provides services and supports for people with developmental disabilities is continuing to change lives across Missouri.

Under the personal leadership of Governor Jay Nixon, the Partnership for Hope program set into motion a unique collaboration between local county developmental disability boards, the Missouri Department of Mental Health and the federal Medicaid program. The first of its kind in the nation, the Partnership for Hope program has the additional benefit of providing many services that traditional Medicaid programs do not, such as dental coverage and employment support. It also helps with transportation, housing, technology, personal assistance, as well as physical and behavioral health.

In October 2010, 36 counties and the City of St. Louis enrolled 470 individuals, but within two months, the program expanded to 37 more counties and over 1,000 individuals were enrolled in the first year. To date, 99 counties and the City of St. Louis are participating. The program provides up to \$12,000 in services per person per year for individuals with developmental disabilities; however, most participants only use an average of \$8,000 a year.

"This program exemplifies the best of federal, state and local government working together to improve the lives of Missourians with disabilities", said Governor Nixon.

Prior to implementation of the Partnership for Hope program, demand for home and community-based services resulted in a large backlog of Missouri families waiting for help. Because of the backlog, many families waited years to receive the services they needed. Priority had been given to individuals in crisis, such as individuals who were homeless or whose primary caregiver had passed away. In many of those

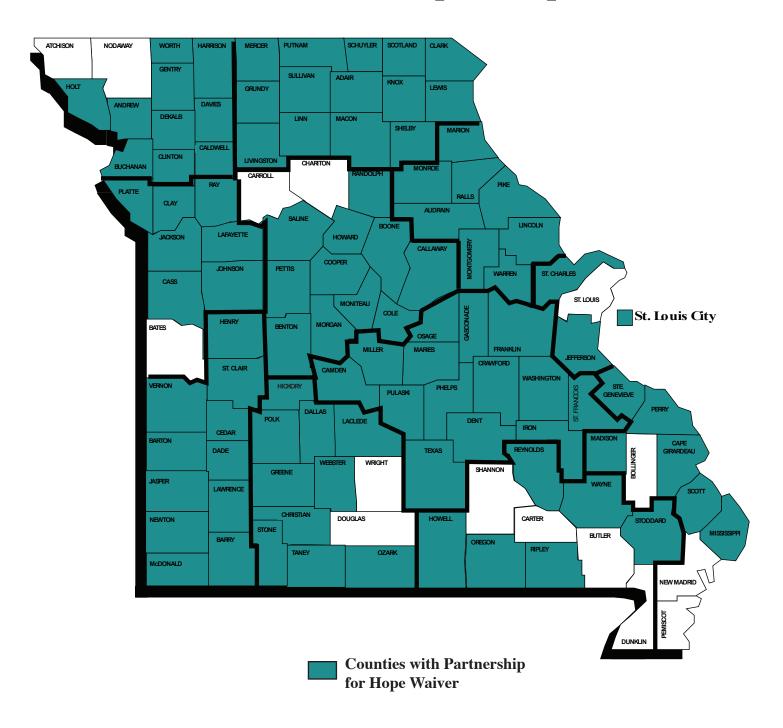
cases, residential or institutional treatment became the only option.

The ultimate goal of the Partnership for Hope program is to have every county in Missouri participating and to eliminate the in-home waiting list for Medicaid



eligible individuals needing developmental disability services. Working together the state of Missouri is helping individuals with disabilities live healthier, more productive lives.

Division of Developmental Disabilities Counties with Partnership for Hope Waiver





Partnership for Hope Services Summary List

Stories of Hope... Where Are They Now?

The next three individuals who participate in Partnership for Hope were first introduced in the Stories of Hope included in the Annual Report in October 2011. Their stories remind us of what each individual needed when they first enrolled in Partnership for Hope (PfH) services and then share the great strides each one has made, still using the supports provided by PfH.

VISHAL

Vishal Patel became a participant the first year the PfH services were offered. His immediate needs were home modifications that allowed him to continue living at home. Vishal wanted to live with his family but because he is a

21-year-old man it was difficult for his parents and sisters to provide his daily care needs without risking injury to themselves and Vishal. In fact, Vishal had an accident in which a home-made ramp for entering the home from the garage tipped and caused Vishal to fall. He had been on a waitlist for over three years to receive the adaptive equipment he needed. Thankfully, with the help of the PfH supports, his family was able to purchase a stair lift, a roll-in shower with a shower chair, a permanent garage ramp and the physical therapy he needs.

Vishal's sister shares what a difference it has made. "We were lifting him and putting him in the shower, whereas now he goes in and out on his own. He can actually bathe on his own. It's independence for him especially since he's a grown adult and he doesn't want his sisters or his mom to be in there bathing him."

Once Vishal's immediate needs in the home were taken care of the PfH services enabled him to receive employment supports that helped him get a real job. Initially, with the support of a job coach, he volunteered once a week at a movie theater in his home town. Vishal is very social and has a great sense of humor, which helped him in his role as a ticket taker in the theater. In fact, he did such a good job as a volunteer that the manager of the theater offered him a paid position. He started on January 5, 2013.

Vishal noted, "My case worker told me about Partnership for Hope and she helped me get into the program and my life changed forever."





Vishal Patel

"Partnership for Hope. . . my life changed forever."

Stories of Hope... Where Are They Now?

LUCY

Lucy Spare is a fast learner and despite her diagnosis of mild intellectual disability and Downs Syndrome, she never accepted that there were any obstacles that she couldn't overcome. Lucy Spare has been participating in the Partnership for Hope (PfH) program since February 2011. Initially, Lucy and her parents sought supported employment services which helped her explore and learn new skills. In addition to pre-employment skills, Lucy learned to recognize what is appropriate attire and how to communicate in a work environment.

Lucy took her new skills and strong, new, self-confidence into the real world to try and land a job. In March 2013 Lucy began working at the University of Missouri- Kansas City, Institute for Human Development (UMKC-IHD), where she works as a clerical aide in the People First of Missouri office. Lucy is very good with spelling and grammar and in her position she is able to help produce letters and reports for the People First membership as well as other documents that are used internally. Lucy performs clerical tasks such as filing, labeling, and typing.

Lucy now uses PfH support for transportation. She works at UMKC-IHD three days a week, and also goes to a special arts-based day program two days a week called "Imagine That!" This program at Resources for Human Development in Kansas City gives Lucy the opportunity to participate in a variety of artistic endeavors including painting, drawing, sculpting, and music. People who participate in the "ImagineThat!" program are considered professional artists and have the opportunity to display and share their art work. Lucy's work has been displayed at an art fair in Kansas City known as First Fridays.

According to Lucy's parents her success and increasing independence helps them feel more confident about the future. They are grateful Lucy has had all the wonderful opportunities that she has had and they love that she has new friends. Lucy's mother, Diana Spare, says, "The big thing for her is that she has a social life that she didn't have before the Partnership for Hope program."

PARTNERSHIP
FOR HOPE



Lucy Spare

"... she has a social life... that she didn't have before Partnership for Hope."

Stories of Hope... Where Are They Now?

NORMA

Norma Anderson has always loved animals and after enrolling in the Partnership for Hope (PfH) program in 2011, she was able to land her dream job at the Central Missouri Humane Society taking care of cats. The first services Norma received helped her learn important employment skills and today she is taking specialized classes to learn how to become a dog groomer.

"The animals like me and accept me as I am," Norma explains. "They are responsive to me and love me no matter what."

Norma has Asperger's Syndrome, a form of autism that can make ordinary social interactions challenging. During the 2013 legislative session, Norma was asked to testify in front of a Legislative Budget Committee about the benefits of the PfH program. Her grandmother, Fern Anderson, said it was a remarkable and wonderful experience. After Norma gave the group her heartfelt endorsement for the PfH services, she received a huge round of applause from everyone in the room.

"For the past two years Norma has been involved in a number of opportunities and met so many people who have helped her. I have seen a huge turn around with her social interaction and eye contact. It's made such a change in her life and I know this wouldn't have been possible without Partnership for Hope."

While Norma looks for a job in the dog grooming business, the PfH services continue to help her with classes in social skill improvement and social interaction. She is looking forward to an upcoming class on healthy relationships. Once Norma finds her new dream job, she will rely on the PfH program to help her with transportation to and from work.

"My goal has always been to make Norma as independent as possible," said Fern, who has raised Norma since she was four-years-old. Thanks to the PfH program, Fern is confident her granddaughter will be ready for what the future brings.





Norma Anderson

"My goal has always been to make Norma as independent as possible."

-Fern Anderson

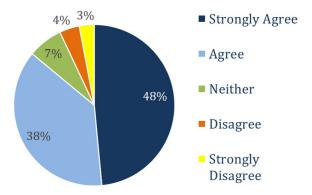
Keeping Families Together

Providing the necessary services and supports for an individual with intellectual and developmental disabilities often impacts his or her whole family. With Partnership for Hope (PfH) supports, family members are able to have a break from providing full-time care so that they can pursue their own interests or just enjoy family time. The PfH program can impact the employment as well, allowing parents to return to work or increase their hours due to the services their child receives through the PfH program.

The PfH services also improve the lives of individuals and their families by allowing people to stay in their own home or with family. A relatively modest amount of funds provides much needed and often long awaited services and supports such as day service activities that help an individual develop the skills he/she needs to be successful in life, and home modifications to allow him or her to live more independently.

The University of Missouri-Kansas City, Institute for Human Development, UCEDD, did a recent study on the PfH program for the Department of Mental Health. In this evaluation families responded to a retrospective survey asking them to reflect on aspects of their lives both before enrolling in the PfH program and after. The vast majority (86%) of families were highly satisfied with the supports and services they receive through the PfH program.

"Overall my family is satisfied with PfH"



The study also looked at the impact on the Family Quality of Life. Results found that the PfH services had the strongest impact on the emotional well-being of the family; in particular, it enabled families to find the support they need to relieve stress. Families also commented that participants had more opportunities to make new friends. The following are some quotes from participants, family members and service providers that illustrate these results.







Emotional Well-Being

"It's given me hope...It's like I actually fit in. I can't even begin to tell you the difference it's made for me. I used to be shy and I used to be in my room all the time. I didn't used to talk to anyone. Because I was able to get help through Partnership for Hope, I am able to go and do a lot more and I don't get worn out as easily. Now it's like a brand new life. It's just like everyday living; the only difference is I don't have to depend on my family as much. It's a lot more enjoyable for me. And I like that I get a chance to actually be a part in the decisions that are being made." *Participant - Jasper County*

"Certain things like the weather impedes me going out – really, really cold days it's hard for my body to work and really, really hot extremes, effects my movement too. With the Partnership for Hope I have been able to get out and still live, so to speak. I just want to live. And I think for me the Partnership for Hope has given me back that feeling that I am living." *Participant - Greene County*

"Without the Partnership for Hope waiver I wouldn't be able to work. I was sitting here educated and willing but unable to do anything...because I did not have anyone to provide the services that my child needs. I'm now able to be gainfully employed. I want to be dependent on my own income. I remember when they first put us in the program. It was completely life changing for me." *Mother, Camden County*







Making Friends

"They do educational activities two days a week where he learns phone numbers – our phone numbers, writing, and reading. Then one day a week he gets to go play darts and pool. We pay for activities, but they take him. He also goes with his personal assistant one or two nights a week to workout at the YMCA. He's happier, he's having his own life, but yet he still gets to live at home. He's got more friends, a lot more friends and independence from us because we won't be around forever." Parents - Marion County

"Our son receives supports to be able to have a job. He enjoys his job very much and he has friends there and he's with his own peers. I think that makes his life more enjoyable and a better life for him."

Parents - St. Charles County









Creating Supports

"If the yard was muddy we would have to go to a car wash and wash off his wheels and stuff before we could go to any doctor's appointments or anything. The bottom half would be so muddy, even if we didn't get stuck we just had to make that a part of our routine. If it was snowing, there was just no way to get him out. It was literally a nightmare. There were several times when I just cancelled appointments if I knew it was going to be real bad out simply because I knew we couldn't get from the house to the van without getting stuck. And I was always so afraid that we wouldn't be able to get him out.

The Partnership for Hope allowed a local agency to step in and build us an actual ramp that we weren't nervous about. They also got us a sidewalk to keep from getting stuck. That has been such a blessing. Now we don't have to stop by the car wash and wash his wheelchair." Mother - Jasper County

"A gentleman in our area, all of his supports in life had died. Including his mother, his fiancée, everybody had died. He pretty much lived in a little room that was secluded. When we were able to get him a Partnership for Hope waiver spot, we were able to get him moved into an apartment. He now has supports in the home. He's learning skills that he never would have learned before. Not only is he learning, but he's doing stuff that he never would have been allowed to do

before because he didn't have the opportunity. He is experiencing things now that we usually experience as a young person and he's in his 50s. He's volunteering at the humane society and the food shelter. Like a real work environment. He is finally getting to experience that." Service Provider - Henry County







Relieves Stress

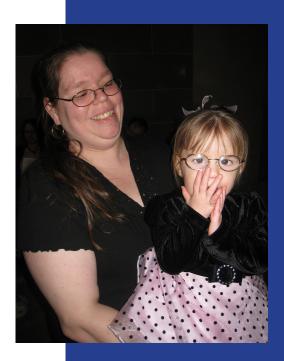
"I got to the point where mobility was becoming an issue because of the disease, the deterioration of my muscles and the fatigue process. For my family's sake and my staff's sake and the people that know me, I felt like I was making them worry too much about me, because I'm the kind of person that if I wanted to do something – I'd go. If I had to cross a busy intersection – I did it. But I knew that with my disease process it could have become tricky. So with Partnership for Hope, I have somebody with me and if there is ever an issue, I didn't have to worry and my family didn't have to worry about me. Now my family can be my family and not my caregivers. And there's a big difference." Participant - Greene County

"The Partnership for Hope support allows me to get out and have a break and do my grocery shopping and not have to worry. It not only allows me to have a break, but my son can have a break because believe it or not he gets tired of me. We're together 24 hours a day; I even sleep in his room most of the time just because I'm worried about one of his hoses falling off. So that time away, knowing that someone's going to stay right there, and I know he's going to be okay is a huge relief for the both of us." Mother - Newton County

"It wasn't that you couldn't use a standard dental person to treat her teeth; she just had a fear of it. So the waiver was such a tremendous blessing. Not just financially but from a psychological standpoint. It soothed her so much that she wasn't afraid. The dentist put that bracelet around her like they do in the hospital, even with her little stuffed animal that she brought in; they put a little bracelet around him too. ...13 cavities and 1 extraction. It was a big ordeal. It took a full day. She's not afraid to go to the dentist now for just routine examinations and cleanings. She's not afraid."

Father – St. Charles County





"...often just a little bit of help can make a world of difference."

- Governor Jay Nixon

How Do I Get Partnership For Hope Services?

Steps to Sign Up

The best way to learn more about the Partnership for Hope (PfH) services and to see if it is right for you or your family is to contact your local Senate Bill 40 (SB40) Board. A complete list of all the SB40 organizations is provided for you on page 16.

Initiating PfH services always begins with the individual, a family member or a support coordinator recognizing that the individual might be eligible and would benefit from the PfH supports. Often it is at a point when something must be done or the quality of life for the individual and/or family would begin to decrease.

Here are some basic steps to follow:

- 1) Regardless of who initiates the conversation about the PfH services, determining eligibility is always initiated by a key support coordinator who has been approved by the DMH, Division of Developmental Disabilities to provide targeted case management. The first thing the support coordinator does with the individual and the family is develop an Individual Support Plan (ISP). This plan simply documents the individual's support needs.
- 2) Next, the support coordinator determines the ICF/DD level of care using a tool called the Missouri Critical Adaptive Behaviors Inventory (MOCABI). This tool is specific to Missouri and helps identify functional limitations and needs. It confirms and documents a person's intellectual disability or related condition, a need for continuous active treatment, and an observation and assessment of the person's physical, mental and environmental conditions.
- 3) The support coordinator then helps the individual and the family to identify the best services option that will allow him/her to get the needed supports.
- 4) The support coordinator works with the individual and the family to identify a provider to deliver the services needed and helps to develop a services choice statement.
- 5) If the PfH program is identified as the best choice for this individual, then the support coordinator completes a PfH Prioritization of Need (PoN) form. The form is then sent to the closest DMH Regional Office for the director's approval and entered into CIMOR. The request is then sent to the DMH Central Office for final approval and enrollment.



STEP 1

Develop an Individual Support Plan

STEP 2

Determine the Level of Care

STEP 3

Identify Best Option for Services

STEP 4

Find a Provider and Create the Services Choice Statement

STEP 5

Request Enrollment in PfH

What Services are available?

Employment

Employment services can support a person to learn about jobs, build skills to be successful in a career, get support when starting a new job, or have ongoing support during employment.

Health

Health services can help a person access dental care, obtain special medical equipment and supplies, or get assistive technology to help maintain independence and well-being.

Therapy and Skill Development

These services can help an individual access speech therapy, physical therapy, occupational therapy, or day services and supports.

Assessment and Planning

Assessment and planning services can provide behavioral assessment and supports to foster social skills, independence, and integration into one's community. These services can also help families and individuals better understand and manage their services and supports.

Environmental Accessibility/Accessible Housing

These services can help families and individuals make modifications to their home, to receive personal assistance to help individuals be more independent, and to support transportation needs.

Temporary Residential Services

This service provides care outside the home when family members/ caregivers need to be away.







Resources

How Can I Learn More?

The best way to learn more about the Partnership for Hope program and see if it's right for your family is to contact your local Senate Bill 40 (SB40) Board. Listed below are the SB40 organizations that can connect you to the Partnership for Hope Services.

Adair	660.665.9400
Andrew	816.324.7302
Audrain	573.581.3953
Barry	417.385.4157
Barton	417.347.7010
Benton	417.777.7315 ext. 811
Boone	573.874.1995
Buchanan	816.364.3827
Caldwell	660.646.1513
Callaway	573.642.1792
Camden	573.317.9233
Cape Girardeau	573.204.3617
Cass	816.380.7359
Cedar	417.385.4157
Christian	417.551.4901
Clark	573.735.4282
Clay	816.792.5255
Clinton	816.740.4344
Cole	573.634.4555
Cooper	660.882.5112
Crawford	573.438.2866 ext. 8
Dade	417.385.4157
Dallas	417.777.7315 ext. 811
Daviess	660.663.2834
Livingston	660.646.1513
Macon	573.735.4282
Madison	573.783.3770 ext. 17
Maries	573.897.2991
Marion	573.248.1077
McDonald	417.347.7010
Mercer	660.646.1513
Miller	573.348.3751
Mississippi	573.547.6639
Moniteau	573.796.6131
Monroe	573.735.2578
Montgomery	573.564.5045
Morgan	573.569.4240
Newton	417.347.7010
Oregon	417.764.3678
Osage	573.897.2991
Ozark	417.335.4135 ext. 302
Perry	573.547.6639
Pettis	660.826.4401 ext. 398
Phelps	573.426.2822
Pike	573.324.5493
Platte	816.891.0990
Polk	417.777.7315 ext. 811
Pulaski	573.855.7240
Putnam	660.665.9400
Ralls	573.231.6559 ext. 106
Randolph	660.882.3686
Ray	816.470.7140 ext. 301
nay	313.47 3.7 1-10 EAC. 301

DeKalb Dent	816.449.5481 573.729.4738
Franklin	636.583.5801 ext. 1208
Gasconade	573.437.5800
Gentry	660.726.5246
Greene	417.886.0404
Grundy	660.646.1513
Harrison	660.726.5246
	660.885.8131
Henry	417.777.7315 ext. 811
Hickory Holt	660.726.5246
Howard	660.248.5233
Howell	417.284.3966
Iron	573.438.2866 ext. 8
Jackson	816.363.2000 ext. 207
	417.206.7373
Jasper	636.282.4431
Jefferson	
Johnson	660.747.9404
Knox	573.735.4282
Lafayette	660.584.3101
Lawrence	417.385.4157
Lewis	573.735.4282
Lincoln	636.462.7695
Linn	660.258.2877
Reynolds	573.689.2896
Ripley	573.996.3867
Saline	660.826.4401 ext. 398
Schuyler	660.665.9400
Scotland	660.665.9400
Scott	573.335.0134
Shelby	573.735.4282
St. Charles	636.939.3351
St. Clair	417.385.4157
St. Francois	573.756.0595 ext. 109
St. Louis City	314.421.0090
Ste. Genevieve	573.883.3330
Stoddard	573.624.5212
Stone	417.335.4135 ext. 302
Sullivan	660.665.9400
Taney	417.335.4135 ext. 302
Texas	573.426.2822
Vernon	417.385.4157
Warren	636.456.4347
Washington	573.438.2866 ext. 8
Wayne	573.998.2875
Webster	417.830.2494
Worth	660.726.5246





















"The Partnership is helping keep families together."

- Dr. Keith Schafer Director, Department of Mental Health



This report produced by the

Missouri Mental Health Foundation in cooperation with
the Missouri Department of Mental Health,
the Missouri Association of Counties for
Developmental Disabilities Services
and the Governor's Office.







Developmental Disabilities Services

